



EB to ME

Reflections from Members of the EB Community.

"We brought home our daughter from China in 2015, and she has EB. We knew she had EB before we said "yes" to her; knowing ahead of time is an opportunity most families don't have. We were able to prepare as best we could, but even so, the wound care learning curve is steep. EB has made her compassion for others strong; when she sees someone hurting or upset, her response is to try to comfort them. She is one of the strongest people I know, and our family is blessed to have her. We cannot imagine our lives without our butterfly."

- Whitney R.

"I grew up with a mom that has EB. Watching her get up every morning put on bandages and then put on her clothes was a normal thing to me after a while. Not until I was in High School did I notice how brave she was to get up every morning and continue with the day. Every day she helped me with my school work and encouraged me to be kind and helpful just like her. My mom did not let anything stop her, she was a religion teacher, Girl Scout leader and ran the vacation bible school program at my church. One day I hope that there is a cure for "the worst disease that you've never heard of," but for now I can only continue to raise awareness and raise money for families in need with EB for help with bandages and informational help. Now when I wake up with a sore knee or when I do not feel well I then realize that it could be worst and I could be just like my brave mom."

- Kelly McCauley, Young Leadership Committee

"I discovered EB through watching a documentary. As I researched the disease I became determined to help Debra and EB patients as well as spread awareness. I got involved to help others but it really ended up saving me in the end. Seeing a person with EB really puts things into perspective. In the years following I had gone through some major losses in my life and very difficult trials and tribulations, but something always kept pulling my focus back to Debra. I realized that I could either sit there feeling sorry for myself or I could step up and do something to help someone else. I got the chance to create my own event, fund raise, and was finally given the opportunity to intern at Debra. Last week I met some of these kids for the first time and they made me see why it was all worth it. Debra is an organization that will "give you the shirt off their back" and really go above and beyond. I'm proud to have the opportunity to work with these amazing individuals. Learning about EB transformed my life and gave me the ability devote what I have to those truly deserving."

- Desiree Swendsen (debra of America Intern)

"We received our big box of blessings from debra of America at the end of last week. Thank you so much for everything! Ethan loves the teddy bear!"

- Karolyn M.

"What does EB mean to me? EB means loving and accepting my child for all of his unique abilities. Overcoming the fact that what our plan for our child is different from what God had planned for us. Loving and accepting his plan! Submitting to the fact that he is in control and will guide us through the EB journey. EB is a cruel disease that comes with suffering for the entire family. It is a life filled with heartache and sadness. EB means celebrating the happy times, the smiles, the little things we take for granted, and realizing what's really important in life. EB has taught me to love and accept things I can't understand. EB has given me a drive to be there for others, help, and lift them up whenever we can."

- Maranda Asa (Mom to Madden with EB)

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“Living with EB for the past 61 years is the word Frustrating, with a capital F. It is Frustrating that we with EB can't take a beautiful hike in nature. It is Frustrating when you go horseback riding and end up with two raw inner thighs and your pants stuck to your legs. It is Frustrating when you have to say no to a date of dancing. It is Frustrating when you go ice skating and find that you're pretty good at it and then can't walk for a week. It is Frustrating having to sit out of gym class. It is Frustrating being left behind. And the "can't" is in our vocabulary because there are many things we just "can't" do no matter how much we wish we "can."

- Toni K.

“I have Dominant Dystrophic Epidermolysis Bullosa. EB is a never ending battle. It can either bring out the strength in you or it can break you down. It is forever wearing the scars of your journey for everyone to see and the bandages of the fight you are currently fighting. It is knowing you are unique and the fear that others won't understand. It's not becoming a victim and always staying a fighter. It's knowing your beauty and not afraid to show it to the world. As a mother of a son who has it as well, it is power of empathy and love to show him he should not give in to self-pity thoughts or feeling like he will always be a victim of the disorder. It's holding him when days are tough and the wounds are bad, but making him get up and keep fighting. It's looking into your child's eyes and seeing the innocence that still exists even with the world trying to take it away. Bandages and scars are all others can see but strength and courage is what is really in each and every person with EB.”

- Danielle Slocum

“I am a 67 year old female and have had EB all of my life. I am not sure what type I have, but have been told that it is probably Junctional or Dystrophic EB. The older I become, the worse my EB becomes. I have extreme itching and blistering. No one, including my own 3 children, 8 grandchildren, 3 siblings, or older family members are affected by EB. I don't like to meet strangers because of how some stare at my scars.”

- Dianne B.

Stealer of Peace

Nemesis

Thief

Stealer of Peace

Voracious predator

Stalking

Taunting

Demanding & attaining my absolute, undivided attention

Exhausting

Invading my every thought

I cannot outsmart you

I'm on the run

Pursued by an insidious, insatiable beast

Unrelenting, untamable

Crafty, elusive opponent

Wreaking havoc whenever, wherever

In its wake

The wounded

The heartbroken

The mentally weary

You despicable, heinous, monster

Formidable enemy

Your reign must end

Be forewarned

We are banding together

Gathering resources

With great resolve we are launching an all-out campaign

We intend to turn the tables

We intend to bring you down!!

- Donna S. (EB mom)

“I remember when my son was born; he was missing skin from his hands and feet. His condition continued to deteriorate in the next couple days after his birth. I felt terrified and alone. Receiving the diagnosis of EB brought little

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comfort. It was devastating and to say it changed my life forever is an understatement. EB means a great many things to me now. It means having to reach inside and find a strength I never knew existed before. It means having to put on a brave face even when I feel helpless and afraid. Watching someone you love so much suffer and not be able to take it away is something that, at times, seems impossible to endure. It means many nights filled with anxiety and tears because there is no time or place for that during the waking hours. It means giving up that fantasy of a future that never really existed and focusing on the present. It means paying extra attention to all the good moments in life. I appreciate and fully enjoy every triumph, every pain free day, every smile, and every hug. It means realizing that every day truly is a gift. Most of all EB means filling my heart with hope instead of despair and fear. I hope that my son will continue to overcome all the obstacles EB causes. I hope that he is able to lead a relatively normal life despite this horrible disease. I hope that he will live to see adulthood and beyond. I hope that someday there will be a cure that will end his pain and suffering.”

- Christina (Alex's Mom)

“My niece Keisy is 7-years-old and is an angel full of light. She lives in the Dominican Republic where it is very hot, humid, and dusty - and where doctors know very little about Epidermolysis Bullosa. She's an honor student and has to be so strong because kids don't understand her disease and make fun of her or don't want to play with her thinking that she is contagious, but still she is determined to go to school and her biggest dream is that one day she will be cured. Thanks to debra of America for all of their support to my family. Without their help, it would be a lot worse for our little angel.”

- Rosa Ramirez

“My son Cole has EB. He'll be 23 in September. I admire his courage and am in awe how he handles himself in the day to day situations that so many people take for granted. Such a cross to carry! I am so thankful for Cole and am well pleased of the man he has become. He has much life and such a life to live! Cole loves people but is also happy in his own company. Cole is a reader and a writer and enjoys stories of survival and apocalyptic nature. Cole is introspective but not shy. Cole does carry a lot inside, he seldom complains and is reluctant to express discomfort or share his pain for fear of burdening his mom or me with it. We remain hopeful for a cure and pray that those who suffer from EB will find peace and a pain free life!”

- Peter Connelly, Baton Rouge, LA

“Our sweet, stubborn little Lily has Recessive Dystrophic EB. We had no idea what that was or even meant. She was breech my entire pregnancy and was born via C-Section, so that's why she's stubborn! In a sense, it saved her life. The first 2 months in the hospital were horrific. No one really knew what to do or how to handle her, and it seemed like every day there was something new and scary we experienced and learned. But with the help of this organization and many others like it, and the help of other parents, Lily has had minimum blisters and wounds. She will be a year old April 18th. We honestly didn't think she'd make it this far. We know we have many more challenges to face as she gets older, but she is a tough kid with a huge personality and I know she can handle anything life throws at her. She's our little flower and we love watching her bloom.”

- Danielle, Lily's mother

“As a mother of a teenager with RDEB, I have a love/hate relationship with Epidermolysis Bullosa. My pregnancy was a normal one. I wanted her to have her dad's dimples, and he wanted her to have my blue eyes. When the doctor placed her on my chest after delivery, I saw those two things in her little round face immediately. Then my world was turned upside down as she was whisked away from me to the NICU. My new chapter in this book of life was just beginning. EB has taught me unconditional love, unbelievable strength, and how great my faith can be. If Harlee had been born an average child, I do not believe I could truly understand the love of a parent for a child. She has shown me strength, courage, and determination that most children/teenagers do not have. She has also shown me it is ok to cry and find that strength through the tears. EB does contribute to every aspect of our life - what we eat, when we go on vacation, where we go on vacation, what clothes we wear, and this is just the tip of the iceberg. She has had so many surgeries that I have lost count. Harlee's pain at times is almost unbearable, but we continue on. We are survivors. I would give my life for a cure for not only Harlee, but the friends we have met on this journey. But if asked if I could go back in time and never have her - my answer would be a resounding no. Without EB and Harlee, I would not be the person I am today. God's grace covers us every day.”

- Suzanne

“My life is a wonderful life and EB is just a passenger! Hi, my name is Christine. I am 61 years old. To me EB is a devastating disorder, but not so bad after I decided to handle it my own way. For anyone who is caring for a child or their baby, I know it is often a matter of life or death. I pray a cure is found someday, especially for the children! As for

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me, I'm doing OK. I've found shortcuts & money saving ways to care for myself. Every day I remind myself how blessed I am to have a husband who is always finding ways to make my life easier. Also I have two talented, healthy children who are so supportive no matter how busy their own lives are, and I have one wonderful son-in-law, who I consider one of my own. About 1½ years ago I lost my right leg to cancer, which was a result of EB. That was a blessing, too. No more cancer and much less pain! I try to keep on smiling, I don't feel sorry for myself and I don't dwell on it. Hey, "Life goes on!"

- Christine

"EB... as a grandmother this rare disease has forever changed my life and the life of my grandson Blake and our whole family. EB is heartbreak and hope. EB is determination and unwavering love. EB is reality and ongoing research. For most, a true life changing event is only read about in the paper or seen in a movie. EB is rare and real. I pray every day that ongoing research will soon bring about a breakthrough cure and it will not come soon enough."

- Kathy Schipma

"I lost my son Robert Joseph Heier on December 9, 2006 due to EB. He was only 5-years-old. My wife and I had a healthy pregnancy and had never heard of EB until it happened. I miss him every day. RIP my sweet boy. Thank you kindly for listening to what EB means to me. God bless all and hoping for a cure someday."

- Joey Heier

"EB is a rare anomaly I've been living with for 40 years."

- Sheila

"I was diagnosed with EB Simplex at birth - and my experience with EB has brought me down some extremely trying roads, but has also led me to so many things that I am grateful for. EB has provided me the opportunity to find the strength within myself to get through anything thrown my way. It has pushed me to feel proud, and more comfortable in my own skin than others without EB may feel. I can attest that it is easy to feel alone when you have such a rare disease. I wish that I were alone, and that no one else in the world had to go through the tribulations that EB brings, but unfortunately my wish has not yet come true. debra of America has helped to show me that I am not alone. Last year, I ran the NYC Half Marathon on behalf of debra of America. I also volunteered at the 2014 debra of America Patient Care Conference, where I met so many amazing people, with whom I share a unique quality, and a unique bond. I am so thankful for debra of America, for my parents, and for every parent that takes care of a child with EB. As difficult as it is to manage a life with EB, it is equally as frustrating and heart-breaking for our caregivers. I know that together, with our strength and tenacity, we will find a cure."

- Gabrielle Sedor (debra of America Young Leadership Committee)

"#EBtoME is every day I wake up and check my daughter for wounds and fresh blisters. That's my life. It all started when my 4-year-old daughter Bayleigh was a baby. Bayleigh was a very happy baby and she hit all of her milestones until it came to walking and crawling. Then she started getting giant blisters on her feet, hands, and in her mouth. EB has been a huge battle for Bayleigh and our family, and I am fighting to try and find a cure. It was very hard to get Bayleigh's school to accept her because they didn't think she was capable of functioning in school. But Bayleigh is a fighter. She fights to be happy every day and go to school and has recently started cheerleading. Currently I am running Bayleigh's Butterfly to help promote EB awareness and sell merchandise to raise money for debra of America. EB means life. EB is our life. I hope one day Bayleigh can live her life without the pain from EB."

- Ashley Templeton

"#EBtoME is a beautiful baby boy in Weedsport, NY named Easton Friedel and the ugly disease that has taken over his body. It is also about the strength of a family and willingness of a community to come together to fight the fight and keep the hope."

- Michael Benny, News Anchor, WTVH-TV, Syracuse, NY

"The first person I met with EB was Abbie Evans. I had never heard of EB, but I was briefed on the basics right before I met her. And to my surprise, the most noticeable thing about Abbie was not her skin or her bruises, but her warm smile and vivacious personality. EB was something she dealt with every day, but it never defined her or let it stop her from doing what she wanted to do. Seeing someone with such a fierce, unstoppable desire to live, redefined EB to me from something more than a disease, to an outlook on life."

- Jessica Miller (Editor of the documentary, "Butterfly Girl")

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“Epidermolysis Bullosa was first mentioned to me 15 years ago, as a distant relative gave birth to a daughter who was diagnosed with EB. To be honest, it was one of those things you are told about, empathize with, but without further discussion fades from thought. Four years ago, through my work, I came face to face with EB, and boy, what a wakeup call. I have had the honor since of meeting parents, caregivers as well as children and adults with various forms of EB. To answer what #EBtoME is grows in complexity each day, but I will try to touch on some of it. Priority - priorities change daily, hourly and minute by minute for us all. When I see the priorities of those with EB and their family around them, it gives a whole new perspective. Pain control, protection from injury, mental anguish and a host of issues that I take for granted is something these people face every minute of every day. Empathy - empathy for those affected, but more importantly using empathy to foster action. Education - education and awareness are also key to enacting action. Love - love is often hard to describe, but when you witness the interactions of EB families, it is first and foremost. Hope and Research - that is what is taking place and again there is awe inspiring research and huge efforts made by families and those with EB to help find a cure. The children and adults should be so very proud of what they are capable of and what they face with strength and determination each day. These children, adults, families and caregivers show the world the very best of humanity, and my personal admiration grows every day.

- Dan Sharp (CEO, Skinnies Woundcare for EB)”

“I am 72 years old, a lifelong sufferer of EB Simplex. My father had it too and I remember how he suffered with blistered feet. Unfortunately, we are from Hawaii where it is hot and humid, both enemies of EB. My schools principals refused to understand and demanded that I wear shoes even though I found I could wear flip flops with ease. These were difficult times. I thought they had ended when I graduated, but no, the school rules continued to be a problem when my own children, both of whom have EB Simplex, began to attend school. Thank goodness for debra of America’s EB Classroom DVD. My grandchildren have benefitted greatly from that wonderful and informative resource. We knew so little about this condition and neither did doctors at the time I was growing up. I have had to learn so much on my own through experience because there was no debra of America to offer resources and information in my early years. The other best thing that has happened is when debra of America sent me some preparations for wound care. I thought of my Dad who suffered so much. In fact, I made my last donation to debra of America in his name just to remember and honor all that he had suffered. I’m grateful to debra of America for making all the newest information available to us. I hope and pray that one day, enough research will give us all the precious relief we need.”

- Vickie V.

“What does ‘EB to Me’ mean? Well, to me it means a gorgeous, intelligent 16-year-old boy who thinks life is a giant adventure! My son’s EB dictates every moment of his life, but still he manages to greet every day with excitement and enthusiasm and dreams. I have by default become a mini-EMT and RN. I’ve met some of the strongest, most amazing doctors, nurses, dietitians, parents, researchers, and beautiful and brave children. It is a ‘club’ none of us want to belong to, but it is an incredible group. Thanks to organizations like debra of America, the word of this condition has spread and momentum is growing for fundraising for the most important thing: a cure. Thank you to everyone who links arms and supports each other through the difficult journey of EB.”

– Patsy, mother of Shane, an amazing 16-year-old boy who has a combination of RDEB and DDEB

“I never heard the words Epidermolysis Bullosa until my beautiful son Lucas Patrick came into the world. Lucas was born with the most amazing blue eyes and I instantly fell completely in love. Everything seemed perfect. But within a few hours Lucas began forming blisters on his skin and inside his mouth. By the time my son was three weeks old, with the exception of his beautiful little face, his entire body was covered in blisters. The doctors informed us that Lucas had junctional herlitz EB and his life expectancy was less than two years. Every day with Lucas was a gift and each day I was in awe of the courage and strength my son showed. There were many days that I would be crying and upset because I couldn’t make him feel better. I couldn’t fix this. I couldn’t hold my own child without causing him pain. But on the days I was most upset Lucas would stare at me with his bright blue eyes and I swear it was as if he was saying, “Mommy I’m okay. This is okay.” It’s like he knew he was meant for bigger things than this world. At just five weeks old, my baby boy died in my arms. EB forced me to do the one thing a parent should never have to do, to say goodbye to their child. Over the past three years since Lucas’ death I have witnessed his story inspire others to raise awareness of EB and join our quest to find a cure. We have held three annual Love For Lucas fundraisers benefiting debra of America and I am truly humbled by the outpouring of love and generosity we have received. I have been honored to meet other EB families from all over the country, and just like my own son, the butterfly children of the world astound me with their bravery and determination. EB stole many things from me. I will never hear my son say “Mama.” I will never see him smile. I will never see him take his first step or discover the amazing beauty this world has to offer. I will never get to teach him all the things a mother is supposed to teach her son. EB

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shattered my heart into a million pieces. But when I feel the saddest my Lucas sends me butterflies to let me know he is okay and still right next to me. EB has taught me to love deeper and cherish every moment I have with those I love, for tomorrow is never promised. I will spend the rest of my life fighting to find a cure for EB so that one day no child has to suffer the way my little Lucas did and no parent ever has to say goodbye to their child because of EB.”

- Nicole Hardman

“A few years ago, I was assigned to a new role as a Dedicated EB specialist at Edgepark Medical Supplies. Having been in the medical supply business for several years at that point, I was very comfortable in dealing with a variety of serious medical conditions. I soon came to realize though, that EB is unlike any other affliction I had previously dealt with. Learning about the disease, being educated by some of the best clinicians in the country, and working with the patients and their families has forever changed me. The disease is shockingly awful, but those suffering from it and working toward a cure are some of the most remarkable people I could ever hope to know. I have learned invaluable life lessons from these courageous people, and am passionate about repaying them for that with any support I can give. This holiday season, our whole company will be fundraising to support debra of America! I am thrilled that we will be contributing to such an important cause; and look forward to spreading a deeper awareness and understanding about EB throughout my own organization.”

- Ruth Barnum (Edgepark Medical Supplies)

“The day my daughter Mercedes was born was the happiest day of my life. She was a very healthy baby from day one, but there were clues that something was just not right. After visiting the pediatrician numerous times for what we passed off as sensitive skin and thrush, Dr. Rabon began to get more and more concerned. Mercedes was admitted to the hospital and had every test under the sun run on her only to come back negative. She was so healthy! So why the loss of skin, why the bleeding when she had her bottle? One Sunday, with huge blisters encompassing each heel, it dawned on Dr. Rabon as we left his office. He ran out to the parking lot to catch us and share his thoughts. We were terrified when we read the brief description and we took a trip to MUSC the following week for an official diagnosis. The day Mercedes was diagnosed with EB she was 4 months old. My world came crashing down; this beautiful, healthy little gift would be in constant pain every day. The guilt I still carry with me daily is indescribable. Despite a scary, unexpected diagnosis, Mercedes has shown me what true courage is. She doesn't care if something will hurt, she tries anyway. She doesn't let blisters slow her down, she still runs and jumps and lets herself get hurt. She doesn't let bandages get in her way, she still just wants to be a kid. We have grown to be a part of a community of EB butterflies that shows how resilient the human spirit can be. Even through all of the difficulties we face every day, pain, financial strain, bullying, I wouldn't trade a moment I have had with my fragile girl. She is truly the most precious gift.”

- Erica Price

“My granddaughter was born 9 years ago with EB. I know how difficult it has been for my daughter, both emotionally and financially. In fact, when my granddaughter was first diagnosed, the insurer didn't even have a treatment code for EB. I wish more could be done for my granddaughter who handles her EB very well. My wish for my granddaughter is that the people she meets treat her kindly and with respect, and with the understanding we all deserve. I wish to thank debra of America for bringing the plight of those with EB to light, and hope every day that a cure can eventually be found.”

- Michael Harris

“Although I HATE EB and all it has done to my Jonah the last two weeks especially, I am overwhelmed (and sporadically in tears) over how incredibly loved we are. To know you guys are praying for him, thinking about him, asking how you can help... it's so good. His Kindergarten teacher, Ms. Pabon came over this afternoon, after teaching 11 other kids all morning, to visit with him and bring him audio books (and a cassette player because ours is in storage), Granddaddy Gerry brought us milkshakes and told him approximately 107 stories, his other Kindergarten teacher, Ms. Boone called tonight and let him chat her ear off for 20 minutes to break his monotony, and Mimi MaryKay came tonight with a stack of books to read to him (by flashlight because we had to be in the dark) and spent a long time entertaining both boys. So as much as I hate EB, I think about how much we might be missing out on if we weren't forced to slow down and let ourselves be loved. It's an important thing. To ask for help, to let people into your life, to be real with each other. To be vulnerable. I'm thankful for the hundreds (thousands?) who love and pray for us. And I'm thankful to know it. Fully.”

- Patrice Crump Williams

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“debra of America is doing incredible work not only by helping children and adults with EB receive the best care possible and creating a community to support their family - but also by funding the ongoing research for a cure. It is by working with the best researchers in the Dermatology Department at Columbia University that I heard about EB for the first time. I could not believe that I had not before then. I immediately felt moved and decided to join debra of America’s Young Leadership Committee to raise awareness and make sure more people know about Epidermolysis Bullosa.”

- Yanne Doucet (debra of America Young Leadership Committee)

“Once you see EB, you never forget it. That’s why I fight EB. That’s also why in the Spring of 2014 after a 10-year hiatus from long-distance running, I committed to run the Pittsburgh Half-Marathon for TEAM DEBRA. Thanks to my debra of America online donation page and the support of my generous colleagues, the EB Advocate team raised more than \$2,500 for EB research. Running generates a lot of great metaphors for life. I lost a toenail during my training – not uncommon for runners. But the pain of losing that toenail really put in perspective the trials of adults and children who live with EB every day of their lives. Sure there was pain. But my nail grew back. Knowing that doesn’t automatically happen for everyone is heartbreaking and downright unfair. People who fight EB everyday inspire me to keep going in my journey to raise awareness and help fund a cure.”

- Christine Hartz, McKesson Patient Care Solutions (formerly National Rehab)

“EB to my family and me is an obstacle. We have EBS-WC, the “mildest” type. I often feel bad for complaining about my pain when I see the other types that are just unbelievable. Our type blisters our feet. Where do we spend our days? On our feet. My dream job is to be a teacher, a career that requires incredibly long hours on your feet. It seems like a very hard dream to achieve, but I’m going to do it. I have a year left in my schooling, and I will be a teacher. My son has EB and my mom has EB. Sharing this condition has brought us closer as a family. And while it’s a sad bond, it’s a strong bond. We’re here for each other when we need to cry from the pain, let each other know when we find comfortable shoes, and even compare our war stories of blister size. EB is a horrible condition that is completely unforgiving, relentless in its pain, and makes everyday life seem almost impossible some days. My heart goes out to those who have it so much worse than my family. We’re all in this together!”

- Melissa F.

“June 21, 2007 changed my family’s life. Joella Gale Murray was born that day; my lovely grandchild was in agony. She was born with EB. June 21, 2014 a seven year old ‘cooking’ birthday party was held to celebrate Ella’s life and her pizza making skills. No way was EB stopping her! But she is still in agony. I marvel at my granddaughter’s bravery and her parent’s ability to make her life as normal as it can be. Every day for them is a prayer for comfort and a cure. Thank you debra of America for working so diligently to have our family’s prayer answered.”

- Janet Murray (debra of America Benefit Committee Member and Grandmother to an EB Child)

“We didn’t know about EB until my daughter was born 7 months ago and everything has changed since then. We thought it would be the most difficult thing to live through, but she has a beautiful and strong soul. We have learned that angels exist. Her name is Altair and she is my hero!”

- Kenia

“There’s so much more available to people with EB today, as compared to decades ago. Unfortunately, we don’t have all the answers yet, and as a person nearing 70, I don’t expect them in my lifetime, but I feel certain that someday we will have a handle on this disorder. Stay hopeful!”

- Karen G.

“To have EB means to have no fear, no room for doubt, no time for second guessing. When you’re up against something so devastating there is no choice but to move forward to the best of your ability. Through my short time with Abbie I learned more about how to live a fearless life than I ever thought possible. Today I hold her with me as a constant reminder that life owes you nothing and never take for granted what it does give.”

- Cary Bell (Director of the documentary, “Butterfly Girl”)

“I’m 41 with Recessive Dystrophic Epidermolysis Bullosa. I didn’t meet anyone with EB until I was 35, so growing up was often lonely and frustrating. Those feelings haven’t changed, however, my perspective has. I spent months, every year, in the hospital, being poked, prodded, biopsied, and having countless procedures, not to mention unbelievable pain, both of which continue to this day. The child life department was instrumental in helping me understand what was happening, why it was happening and how the doctors were helping me. My mother raised me by herself and even though money was tight she taught me, through her actions, to fight for what I wanted/needed

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and to not let EB define me or keep me from accomplishing any goal. I learned to persevere when most people would give in, and I will always do so. Many people see EB as a horrible thing to have happen to them. I won't say my life wouldn't be easier if I didn't have EB, but I also know I would not be the person I am today if I had not experienced all that I have - and I would not change who I am for anything."

- Jennifer B.

"My little brother AJ has EB. He came into my life 6 years ago, and it has never been the same since. It is so hard to think about all the pain he is in, but he is constantly one of the most joyful people that I know. EB has been called "the worst disease you've never heard of". It's incredibly devastating, but there are children and adults with an attitude and heart like AJ all over the world. They can teach us that achieving life is not equivalent to avoiding death. And in the same way, joy is not the absence of pain. There are always going to be difficult things in life, but it's how we respond to those situations that truly matters."

- Andrew Fischer (Filmmaker of "LIVEBRAVE")

"I wanted to write a thank you from the bottom of my heart for your generosity. The Mepilex from debra of America has been a godsend. I honestly can't tell you how much we appreciate your kindness."

- Christy S.

"Ben Jr. was born with Junctional Epidermolysis Bullosa (JEB) and we thought that our lives were going to end right there and then. It felt like my heart was ripped out of my chest, little did we know that this strong, courageous soul, was going to change our lives forever. Ben Jr. may have raw wounds and be wrapped in bandages from head to toe, and eat, speak, and walk with hesitation, but Ben Jr. is changing lives with his smile and determinations. And not only is he a blessing to us, but he is teaching us the true meaning of life and how to live! #stopEB we need a CURE NOW!!"

- Sirena Wiley

"Epidermolysis Bullosa has been a part of my life for the last 8 years. In 2006, I began my work as the debra of America EB Nurse Educator, and I have to say, I hate that EB exists and is so cruel to all of the amazing people I have met over the years. One mom, who lost her baby daughter to EB, asked me how I could work with this nasty disease every day. The answer is easy. Someone needs to answer the phone. Someone needs to be a calm voice in the storm. Someone needs to listen when EB breaks your heart. For now, I am that person. And my hope is for the day when nobody needs me anymore. I live for the day when I can say, "I used to work with EB. It was, "the worst disease you've never heard of"... but that was before they found the cure."

- Geri Kelly, RN

*"Both myself and my brother were born with Recessive Dystrophic EB and as we were growing up, debra of America became a life line for my mother while she was searching for answers and information. EB has a great impact on everyone around you, so it is important to have a support group that parents or people with EB can lean on. I am now a member of the Young Leadership Committee for debra and write a **a monthly blog** about my life. I have had so many people reach out to me with their personal stories that have expanded what I even thought was possible."*

- Andrew Conrad (debra of America Young Leadership Committee, 28 EB)

"I am an EB Grandparent, but I was also an EB parent to 3 of my 4 children. Fifty years ago my first child was diagnosed with EB when he was 2 months old. His EB was more mild and I wrapped his knees and ankles and let him be a normal little boy. My grandson's EB is much more damaging. Shane is now 16 and has been a lesson in courage for his entire life, with EB affecting much of his body. Life handed his family a challenge and they cope with it every day as examples of living positively despite the complications. I wish I could do more or wave a magic wand and take away the pain that Shane endures. Being with Shane is a complete joy because of the attitude and intelligence that he possesses. Life handed him a challenge and gave us all a hero."

- Kathy DiGiovanna (debra of America Tennis Committee Member and Grandmother to an EB Child)

"I absolutely love debra and what they're doing for those with EB. It's nice to know there are people out there working hard to find a cure."

- Kayla H.

*"I would just like to say thank you so very much for your generosity, debra's **Family Crisis Fund** enabled me to use it for my handicapped vehicle. You made it more affordable for me and my parents. I am now a freshman in college at*

Macomb because of your generosity.”

- Ron and Mary H.

“My son and I were fortunate to meet some children with EB at debra of America’s annual benefit. As I prepared for bed that evening, meditation a part of my days end, I reflected back on the experience and started to cry. The decision was made then to not scratch any part of my body for the next 3-days. This mind challenge allowed me to experience just one piece of what it would be like to live life with this terrible condition. I asked the universe to heal these gentle souls. I realized that EB could also stand for “Enormously Brave!” I encourage everyone to try this 3-day challenge.”

- Celeste Onorati (Astrologer and EB Wing of Roses Designer)

“Do you know what it means to have a child with Epidermolysis Bullosa? For me, it means having to thoroughly inspect every centimeter of Shaelynn’s skin every morning and every night. It means taking a sterile needle to every new blister in order to lance and drain them so they don’t get larger and more painful. It means having to console her and apologize while she repeatedly says “no no no” in an effort to get me to put the needle away. It means bleach baths to prevent infection in her many open wounds and dousing her with mass quantities of ointments and dressings and specially designed bandages otherwise intended for burn victims. It means only gentle hugs and kisses and no holding hands, and removing elastic from every diaper. It means ignoring stares and smiling through ignorant comments from people who don’t understand the battle we fight every day. It means all of these things but most importantly it means having a child who smiles in the face of adversity. It means seeing heart, passion and strength in a very tiny warrior. It means having a pint size hero that can laugh when most others would cry. It means seeing all the good that comes with the bad - and knowing in my heart that I am an incredibly lucky mommy to have been blessed with a brave butterfly child.”

- Veronica O’Neill, Mommy to Shaelynn (3) born with EB Simplex

Dystrophic Epidermolysis Bullosa Research Association of America, Inc.

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